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Goal processes & self-efficacy related to psychological distress in head & neck cancer patients and their partners

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A B S T R A C T

Purpose and objective of the research: In this cross-sectional study we used a self-regulation perspective to better understand the experience of psychological distress in head & neck (H&N) cancer patients and their partners. We examined which goals they valued and the extent to which patients and partners experience goal disturbance. Furthermore, associations were explored between goal disturbance, goal re-engagement, (goal)self-efficacy, and psychological distress.

Methods and sample: H&N cancer patients and their partners, recruited from the Erasmus Medical Center Rotterdam ($N = 40$), were interviewed and completed questionnaires, assessing the above aspects of the self-regulation theory.

Key results: H&N cancer patients and their partners experienced goal disturbance from the disease. Such disturbances were in patients significantly related to more psychological distress. Higher levels of goal re-engagement were related to less psychological distress, again only significantly in patients. More self-efficacy was significantly associated with less psychological distress in both patients and partners.

Conclusions: Self-regulation abilities as goal re-engagement and self-efficacy may be screened and used as target in future psychological interventions, given their potential to decrease perceived psychological distress. In view of elevated levels of goal disturbances in partners, psychological support for caring relatives in such interventions is recommended.

Introduction

Unlike most cancers, the treatment-related side effects of head and neck (H&N) cancer such as disfigurement, altered speech and inability to swallow are immediately noticeable in social settings (Weymuller and Bhama, 2007). Vital functions can be affected and minor disturbances of anatomy by surgery or chemo/radiation therapy may lead to significant dysfunction and disfigurement, and hence to psychosocial complaints (De Boer et al., 1999). Recent literature suggests that such psychosocial consequences are not only observed in H&N cancer patients themselves. Especially, when the patient's disease is accompanied by social impairments, the impact of the cancer on the partner's life may be profound (Baanders and Heijmans, 2007). Thus research on the psychosocial consequences of H&N cancer should focus on both patients and their partners (Ko et al., 2005).

Although researchers are beginning to find out more about problems encountered by patients with H&N cancer, the different components influencing their psychological well-being still remain poorly understood (Semple et al., 2004). It has been postulated that it might be fruitful to examine adaptation to a stressful event such as cancer from a self-regulatory perspective (Lazarus, 1993; De Ridder and De Wit, 2006). Earlier research in patients with a chronic illness suggests that such a self-regulatory theory is a useful framework for reaching better understanding of patients' psychological adaptation to the illness (Boersma et al., 2006; Van der Veek et al., 2007; Schroevers et al., 2008). In this research we will use such a self-regulation perspective to better understand the experience of psychological distress in H&N cancer patients and their partners.

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Self-regulation theory and the importance of goals

The definition of self-regulation clearly places goals at the center of the processes. Self-regulation looks upon the individual as an active goal striving agent. People live life by identifying goals and behave in ways aimed at attaining these goals (Carver and Scheier, 1998). Personal goals do not exist in isolation. As discussed in De Ridder and De Wit (2006) they are linked with other goals in a hierarchical structure. Individuals use this structure in order to organize their goals. Mid-order goals are concrete goals that can be achieved within a relative short period. For example, an individual may have a mid-order goal 'to visit terminal ill patients once a week'. This mid-order goal can be linked to a more abstract higher-order goal 'to support others in life'. Having a clear vision of these higher-order goals in life is in itself an important predictor of subjective well-being (Emmons, 2003). Confronting unattainable goals may result in a reduced well-being and psychological distress. This may especially be relevant in the context of having a chronic illness, as the illness may lead to obstacles in the attainment of important goals (Stein et al., 1997; Kuijer and De Ridder, 2003). Studies among cardiac patients suggest that the experience of such goal disturbance is indeed related to more emotional distress, not only in patients themselves but also in their partners (Boersma et al., 2006; Joekes, 2004). Little is known about the role of goal disturbance in psychological distress in H&N cancer patients and partners. Therefore, the first aim of this study is to explore which goals are valued and at the same time examine if patients with H&N cancer and their partners experience goal disturbance and whether this is related to perceived psychological distress.

Goal re-engagement and self-efficacy

The second goal of the study is to explore the role of two factors that have been related to adaptive self-regulation. First, it has been suggested that adaptive self-regulation in the context of obstructed goals depends on the availability of alternative goals (Wrosch et al., 2003). When goals are unattainable, it seems to be important to be able to find renewed purpose in life elsewhere the, so-called *goal re-engagement* (Cameron and Leventhal, 2003). Goal re-engagement may buffer the negative emotions associated with the inability to make progress towards a desired goal (Rasmussen et al., 2006). In this study we will examine to which extent goal re-engagement in H&N cancer patients and their partners is related to their perceived psychological distress.

A second factor that seems to play an important role in adaptive self-regulation is *self-efficacy*. Self-efficacy refers to a person's belief and confidence to perform certain behavior leading to a desired outcome in a particular situation. It has been stated that such a confidence is a prerequisite for actual performance of adaptive self-regulatory strategies (Clark and Dodge, 1999). Self-efficacy has been found to play a central role in psychological well-being in patients with different chronic illnesses (Kuijer and De Ridder, 2003; De Boer et al., 1998). Also among H&N cancer patients with facial disfigurement, self-efficacy appeared to be an important asset in controlling psychological distress (Hagedoorn and Molleman, 2006). In the present study we will focus on two different types of self-efficacy. First, we will examine *self-efficacy beliefs regarding adequate self-management* of a chronic illness (Lorig et al., 1996). In chronically ill patients, higher levels of this type of self-efficacy were related to patient's perception of better health (Kuijer and De Ridder, 2003). Secondly, we will focus on *goal efficacy* which refers to the belief that one has the ability to attain personal goals (Joekes, 2004). Research among cardiac patients found that a greater sense of goal self-efficacy was associated with better psychological well-being (Boersma et al., 2006; Joekes, 2004).

In conclusion, the present study explored the goals being important to H&N cancer patients and their partners and whether they experienced disturbances in these goals as a result of the disease. Moreover, we examined the associations of goal disturbance, goal re-engagement, and self-efficacy with levels of psychological distress. We hypothesized that: (1) H&N cancer patients and their partners experience goal disturbance as a result of the disease; (2) Such goal disturbance is related to more psychological distress in H&N cancer patients and their partners; (3) Goal re-engagement and self-efficacy are both negatively related to psychological distress in H&N cancer patients and their partners.

Methods

Participants

The sample for this study included twenty adult male patients from which ten were palliative and ten curative cases, and, who either were treated for head and neck cancer or had received their palliative diagnosis in the Erasmus Medical Center Rotterdam, together with their female partners ($N = 40$ in total). We decided to include only male patients as the majority in the general H&N cancer population are male and because of possible gender differences in perceiving psychological distress and providing spousal support. In terms of disease phase we decided to work with a cross section of patients treated in Erasmus MC, which are both palliative and curative patients in different disease stages. Patients were included if they finished treatment or received palliative diagnosis at least one month ago. Patients were excluded who were not able to complete questionnaires in Dutch language.

Design and procedure

For this cross-sectional study, data was collected via a battery of validated questionnaires. Regarding the procedure, patients and their partners were recruited and contacted by phone by the H&N surgeon of the Erasmus Medical Center Rotterdam. They were provided with the questionnaire, a letter explaining the content of the study and an informed consent. After receiving informed consent, a date was planned for a home visit to conduct a short interview and to collect the filled-out questionnaires. This was done by one scientific researcher. In total twenty couples were enrolled for this study. One curative patient did not want to cooperate because he found the questions irrelevant. Ten palliative patients called off their participation with main reason: deteriorating physical situation of the patient and some were too busy with other things or in general not interested in participation. This study was approved by the Medical Ethics Commission of the Erasmus Medical Center Rotterdam.

Instruments

Psychological distress

Psychological distress was assessed with the Hospital Anxiety and Depression Scale (Zigmond and Snaith, 1983). This 14-item self-report instrument measures anxiety (seven items) and depression (seven items) using four-point scales. The range for both scales is 0–21. Scores 8–10 indicate possible cases for depression or anxiety, while scores >10 indicate probable cases for depression or anxiety. In a validation assessment of the HADS (Lorig et al., 1996) the reliability for both scales was found to be good. Specifically for head and neck cancer patients, screening for depression can be accurately done with the HADS (Katz et al., 2004). Cronbach's alphas in current study were .91 for patients and .77 for partners for anxiety and .83 for patients and .85 for partners for depression.

Goal importance & disturbance

Goal importance & disturbance were assessed with the Goal Facilitation Inventory (GFI) (Maes, Ter Doest, & Gebhardt, 2002). For each of the 26 higher-order "being" goals such as 'being healthy', patients and partners were asked to report the importance and extent of disturbance in their life on a five-point Likert scale, ranging from 1 = 'not at all important' to 5 = 'very important' and 1 = 'completely disturbed' to 5 = 'not at all disturbed' respectively. Cronbach's alpha for goal importance was .82 for patients and .94 for partners. Cronbach's alpha for goal disturbance was .95 for patients and .92 for partners.

In addition to higher-order "being" goals, we asked patients and their partners about their mid-order" doing" goals. By means of one item they were asked to indicate their most valued personal goal for the coming months. By means of five items, we also assessed people's perceptions regarding disturbances in five mid-order goals, related to work, household tasks, partner & children, family & friends, and hobbies (answer category 1 = not attainable at all to 5 = very good attainable). Cronbach's alphas were .85 for patients and .80 for partners.

Goal re-engagement

Goal re-engagement was assessed with the six-item subscale Goal Re-engagement developed by Wrosch et al. (Wrosch et al., 2003). To cue the goal re-engagement responses, all six items were answered with respect to the most important unattainable goal for respondents since the disease of the patient. The generic sentence that needed to be completed was: "Now I cannot attain this goal any longer……" with example item: 'I seek other meaningful goals'. Cronbach alpha was .92 in both patients and partners.

Self-efficacy related to self-management

Following Lorig et al. (1996) and Kuijer and De Ridder (2003) we asked patients and partners to answer six items on self-efficacy beliefs regarding achieving health outcomes (e.g. 'How confident are you that you can continue to do your hobbies and recreation?'). All items were measured on a seven-point scale, ranging from 1 = 'no confidence at all' to 7 = 'full of confidence'. Cronbach's alpha for this scale was .90 for patients and .84 for partners.

Goal related self-efficacy

Goal related self-efficacy was measured with the Goal And Processes Inventory-Health (GAPI-H-71) (Maes et al., 2003). This subscale consists of 6 items (e.g. 'It is clear for me how I can attain this goal') using a five-point Likert scale, ranging from 1 = 'completely disagree' to 5 = 'completely agree'. Cronbach's alpha for the scale was in the patient and partner group .97 and .93, respectively.

Statistical analysis

First, the scales were screened for normality. None of the scales violated the assumption of normality, except for the depression scale of the HADS and the goal efficacy scale, both with one outlier. Following statistical guidelines to reduce the impact of these outliers, we replaced the scores by the mean score plus/minus two standard deviations (Field, 2005). Next, standard descriptive statistics and *t*-tests were performed to examine the mean levels of goal importance, goal disturbance, goal re-engagement, self-efficacy and distress between patients and their partners. In the patient and partner group separately, Pearson product–moment correlation coefficients were used to examine the relationships between goal disturbance of the higher-order goals, goal re-engagement and self-efficacy on the one hand and psychological distress on the other hand.

Results

Sample characteristics

Table 1 summarizes the characteristics of the studied participants.

Descriptives of study variables

See Table 2 for mean scores and standard deviations of the study variables. Using independent-samples *t*-test, we found no significant differences between patients and partners.

Goal importance and goal disturbance

Table 3 shows mean scores on all 26 higher-order goals, regarding importance and disturbance. A rank order was made for the most important higher-order goals, with the top 5 presented in bold in the column "Importance". It can be seen that the goals *being healthy, ensuring my safety, and treating others fairly* are in the top 5 of both patients and their partners. Also some differences can be observed. Patients attached more importance to the goals *understanding the world around me* and *making my own decisions in life*, whereas partners perceived the goals *supporting others* and *fulfilling my duties to others* to be more important.

The following column of Table 3 shows the "Disturbance" of each of the 26 items, measured with the actual disturbance scores. Experiencing bodily pleasure is the most disturbed higher-order goal for both patients and partners. Furthermore we have added an extra column called "Impact" as we also wanted to examine goal disturbance by looking at goals with the greatest impact

Table 1
Demographic and medical characteristics of head & neck cancer patients and partners.

Characteristic	Patients ($n = 20$)	Partners ($n = 20$)
Gender		
Male	20	0
Female	0	20
Age (M, SD)	60.7 (10.37)	57.6 (11.37)
Education level		
Primary	7	6
Lower vocational/secondary	3	3
Middle vocational/secondary	4	9
Higher vocational/university	6	2
Employment status		
Paid job	6	4
Self-employed person	4	1
Retired	8	1
Housewife	0	13
Volunteer work	0	1
Incapacity for work	2	0
Time of treatment or palliative diagnosis		
<1 year ago	17	–
Between 1 and 1.5 years ago	3	–
T-stage		
T1	0	–
T2	8	–
T3	7	–
T4	4	–
Tx	1	–
N-stage		
N0	9	–
N1	4	–
N2	5	–
N3	1	–
Nx	1	–
M-stage		
M0	16	–
M1	4	–

Table 2
Descriptives of study variables.

	H&N patients ($n = 20$) Mean (standard deviation)	H&N partners ($n = 20$) Mean (standard deviation)
Goal importance	104.23 (10.93)	97.62 (18.86)
Goal disturbance	52.92 (17.86)	56.49 (13.87)
Goal re-engagement	20.05 (5.88)	18.56 (5.15)
Goal efficacy	23.65 (5.31)	21.00 (4.77)
Self-efficacy related to self-management	28.85 (8.26)	28.36 (7.06)
Anxiety	7.69 (4.88)	8.15 (3.34)
Depression	5.65 (3.63)	6.25 (4.46)

Table 3
Ranking of goal importance, disturbance and impact of higher-order goals based on mean scores. Impact = importance × disturbance.

		Importance	Disturbance	Impact
Goals male patients:				
1	Being healthy	**4.60**	2.80	**12.88**
2	Treating others fairly	**4.60**	1.20	5.52
3	Ensuring my safety	**4.60**	2.10	9.66
4	Understanding the world around me	**4.55**	1.50	6.83
5	Making my own decisions in life	**4.50**	2.05	9.23
6	Having fun	4.45	2.35	**10.46**
7	Coming up with new ideas	4.45	1.35	6.01
8	Keeping up my self-confidence	4.40	1.80	7.92
9	Fulfilling my duties to others	4.40	1.70	7.48
10	Supporting others	4.40	1.35	5.94
11	Feeling relaxed	4.20	2.60	**10.92**
12	Experiencing bodily pleasure	4.15	3.10	**12.87**
13	Respecting rules	3.95	1.25	4.94
14	Receiving support from others	3.90	1.65	6.44
15	Feeling connected to the people around me	3.90	1.55	6.04
16	Meeting a challenging standard of performance	3.90	2.60	10.14
17	Having daily activities run smoothly	3.90	2.40	9.36
18	Experiencing excitement	3.80	2.90	**11.02**
19	Learning new things	3.75	2.40	9.00
20	Reaching a higher level of consciousness	3.68	1.73	6.37
21	Doing creative things	3.60	2.35	8.46
22	Feeling unique	3.50	1.75	6.13
23	Discovering who I truly am	3.50	1.65	5.78
24	Doing things better than others	3.25	2.15	6.99
25	Feeling a spiritual sense of connectedness	3.21	2.05	6.58
26	Obtaining more money or possessions	2.80	2.55	7.14
Goals female partners:				
1	Ensuring my safety	**4.65**	2.20	10.23
2	Being healthy	**4.60**	2.25	**10.35**
3	Supporting others	**4.60**	1.00	4.60
4	Treating others fairly	**4.50**	1.90	8.55
5	Fulfilling my duties to others	**4.45**	1.78	7.92
6	Receiving support from others	4.30	2.10	9.03
7	Feeling relaxed	4.25	2.80	**11.90**
8	Having fun	4.20	2.70	**11.34**
9	Keeping up my self-confidence	4.20	2.30	9.66
10	Feeling connected to the people around me	4.20	1.90	7.98
11	Having daily activities run smoothly	4.20	2.75	**11.55**
12	Respecting rules	4.10	1.50	6.15
13	Understanding the world around me	3.90	2.00	7.80
14	Making my own decisions in life	3.75	2.90	**10.88**
15	Experiencing excitement	3.60	2.60	9.36
16	Meeting a challenging standard of performance	3.55	2.05	7.28
17	Experiencing bodily pleasure	3.35	3.00	10.05
18	Feeling a spiritual sense of connectedness	3.31	2.00	6.62
19	Doing creative things	3.25	2.30	7.48
20	Discovering who I truly am	3.15	1.80	5.67
21	Coming up with new ideas	3.10	2.50	7.75
22	Learning new things	3.10	2.50	7.75
23	Reaching a higher level of consciousness	2.90	1.95	5.66
24	Feeling unique	2.80	1.70	4.76
25	Obtaining more money or possessions	2.80	2.35	6.58
26	Doing things better than others	2.40	1.70	4.08

(importance × disturbance) by the illness. Hereby assuming that an important goal that is being disturbed has a greater impact than a less important goal that is being disturbed. Also here the top 5 are presented in bold. In both patients and partners, the illness had a great impact on the goals *being healthy, feeling relaxed,* and *having fun.* In addition, patients also reported an impact on the goals *experiencing bodily pleasure* and *experiencing excitement,* whereas partners reported an impact on the goals ha*ving daily activities run smoothly,* and *making own decisions in life.*

Regarding their mid-order goals (see Table 4), we additionally asked patients and partners to share their most important goal they want to achieve in the coming months. Patients reported that they concentrated mostly on 'building up their physical condition' ($n = 6$), and 'live life as normal as possible' ($n = 6$). Specific goals were celebrating marriage, quit smoking or moving to another house ($n = 4$), leisure time ($n = 3$) and no specific goals ($n = 1$). For half of the partners ($n = 10$) the most important goal for the coming months was to take care of their partner and family, followed by specific goals as celebrating marriage, quit smoking or moving to another house ($n = 4$), live life as normal as possible ($n = 3$), and leisure time ($n = 3$).

When patients were asked about attainability of the five domains of mid-order goals since the cancer diagnosis, goals within the area of work, were lowest attainable (mean 2.4), followed by household-related goals (mean 3.3) and hobby-related goals (mean 3.6). For partners, also work-related goals were most difficult to attain (mean 3.1), followed by hobby-related goals (mean 3.2) and goals related to family & friends (mean 3.6).

Psychological distress

The mean score on anxiety and depression for patients was 7.69 (SD 4.88) and 5.65 (SD 3.63) respectively. For partners the anxiety mean score was 8.15 (SD 3.34) and the depression mean score was 6.25 (SD 4.46). The optimal cut-off suggested by Zigmond and Snaith (1983) in their original paper on HADS is >8. In the patient group 35% scored >8 for HADS-Anxiety and 20% of the patients had a score of >8 on HADS-Depression. In the partner group 60% scored >8 on the HADS-Anxiety scale and 30% scored >8 on the HADS-Depression scale.

Relationships of goal disturbance, goal re-engagement, self-efficacy with distress

Goal disturbance

In patients, more goal disturbance was significantly associated with more depression ($r = .70$, $p < .001$) and more anxiety ($r = .63$, $p < .01$). For partners we found correlations in the same direction but, these associations were not significant (Table 5).

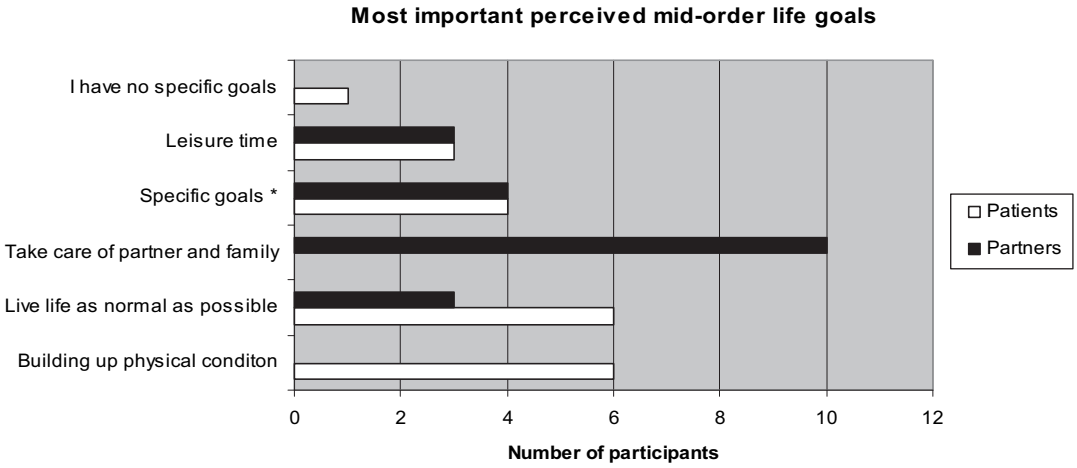
Goal re-engagement

More goal re-engagement was significantly related to lower depression in patients ($r = -.47$, $p < .05$). In partners, more goal re-engagement was not significantly related to less depression. A trend was found for an association of more re-engagement with less anxiety.

Self-efficacy

In patients, more self-efficacy to achieve health outcomes was significantly related to less depression ($r = -.73$, $p < .001$) and less anxiety ($r = -.60$, $p < .01$). In addition, more goal self-efficacy was significantly related to less depression ($r = -.46$, $p < .05$), with a trend observed for less anxiety. A similar picture was found in partners, with more self-efficacy achieving health outcomes significantly related to less anxiety ($r = -.60$, $p < .01$) and less

Table 4
Most important mid-order goals for head and neck cancer patients and their partners.



* Specific goals were celebrating a marriage in the family, quit smoking and moving to a new house.

depression ($r = -.71$, $p < .001$). Also more goal self-efficacy was significantly related to less depression ($r = -.45$, $p < .05$), with a trend observed for less anxiety.

Discussion

This study aimed to examine whether a self-regulation approach could lead to a greater insight into factors related to psychological distress in H&N cancer patients and their partners. Results confirmed our hypothesis that H&N cancer patients and their partners experienced goal disturbance. Such disturbances were especially in cancer patients related to more psychological distress. Also consistent with our hypothesis, more reengaging in alternative goals was related to less psychological distress, but only significantly in patients. Finally, higher levels of self-efficacy were in both patients and their partners related to less psychological distress.

Descriptive analyses clearly demonstrate the presence of psychological problems in this sample of patients as well as in their partners. Both patients and partners reported disturbances in the attainment of their personal goals due to cancer. These levels were comparable with levels of goal disturbance found in another study among cancer patients (Schroevers, 2008). Compared to norms from similar aged individuals from a community sample, patients and partners also reported elevated levels of depression and anxiety: these levels were more or less in line with non-oncological general medical patients from medical outpatient clinics at Leiden University Hospital (Spinhoven et al., 1997). The rate of 20% of total patients scoring >8 cut-off score in completely in line with Katz et al. (2004) who also reported 20% prevalence of clinically significant depression in his study with head and neck cancer patients. Partners in the current study scored in line with another H&N cancer partner group on anxiety (Vickery et al., 2003). These results emphasize the impact of H&N cancer, not only on the patient but also on the partner (Baanders and Heijmans, 2007; Ko et al., 2005; Verdonck-de Leeuw et al., 2007). Such distress in partners may be related to the prospect of losing their partner and feelings of helplessness which can lead to depression (Vickery et al., 2003). As it has been found that distressed partners generally show less supportive behaviors towards the patient (Ko et al., 2005; Hodgkinson et al., 2007), health care professionals should be aware of possible burden of H&N cancer in spouses and may offer integrated psychosocial support (Drabe et al., 2008).

Regarding goal importance, both patients and their partners found it important to feel healthy and safe and to treat others fairly in their relationships. Patients also found it important to make sense out of the world and to make their own decisions. Regarding the short-term, many patients were focused on building up their physical condition and living life as normal as possible. These results show that patients want to move on with their lives. This is in concordance with recent research indicating that H&N cancer patients strive for returning to a normal lifestyle (Goldstein et al., 2008). In addition, partners attached great interest in giving

Table 5
Intercorrelations among outcome variables in head and neck cancer patients and their partners.

		1	2	3	4	5	6
1	Goal disturbance	-	.22	-.39	-.03	.35	.36
2	Goal re-engagement	-.35	-	.32	.07	-.33	-.16
3	Self-efficacy health outcomes	-.59**	.50*	-	.68**	-.60**	-.71***
4	Goal self-efficacy	-.56**	.61**	.57**	-	-.33	-.45*
5	Anxiety	.63**	-.29	-.60**	-.33	-	.57**
6	Depression	.70***	-.47*	-.73***	-.46*	.85***	-

***p<.001; **p< .01; *p<.05.

Note: Correlations in patients are below the diagonal and those of partners are above the diagonal.

support to others and fulfilling social and daily duties. Not surprisingly, most partners were currently focused on taking care of their family. This latter finding may be related to the fact that all partners were females mainly taking care of their partner (Wrosch et al., 2007). Least important life goals for both patients and partners were obtaining more money or possessions and doing things better than others.

Correlational analysis confirmed that in male patients, more goal disturbance was significantly associated with higher levels of psychological distress. This is in agreement with previous studies among chronically ill patients (Boersma et al., 2006; Van der Veek et al., 2007; Joekes, 2004). Although the female partner group experienced similar levels of goal disturbance as patients, the association of goal disturbances with distress was less strong in the female partners. A possible explanation could be found in the difference between male patients and female partners regarding importance of the content of goals. While half of the female partners reported as their most important mid-term goal for the coming months: to take care of their partner and family, male patients primarily concentrate on building up their physical condition. Disturbance of higher-order life goals in female partners seems not to be significantly related to psychological distress as female partners might only focus on their primary short-term goal of 'care taking'. Future research is needed to examine the role of goal disturbance in levels of psychological distress, taking into account both role (patient versus partner) and gender effects.

In accordance with earlier research (Wrosch et al., 2003), we found that more goal re-engagement was associated with less depression, confirming that in case of unattainable goals, the pursuit of meaningful alternatives is of crucial importance for patients' well-being (Schroevers et al., 2008). As mentioned earlier, this may indicate that patients want to move on with their life (Goldstein et al., 2008). At group level, male patients and female partners showed similar levels of re-engagement, which were comparable with a community sample and a sample of cancer patients (Schroevers et al., 2008; Wrosch et al., 2007). The association of goal re-engagement with psychological distress in the female partners was, however, less strong. At this point in time, it can be argued that this has to do with the earlier mentioned importance of the caring role of female partners. We can hypothesize that, as goal disturbance was less strongly associated with a reduced well-being in partners, goal re-engagement may also be less functional for partners' well-being, compared to patients. Being able or not to support and take care of the patient, rather than feeling hopeless and helpless, may be more important or of key importance for partners' well-being.

Higher levels of self-efficacy were in both patients and partners significantly associated with less psychological distress. This confirms earlier research in chronically ill patients (Kuijer and De Ridder, 2003; Joekes, 2004). Especially, having the confidence to manage and continue things in life such as daily duties, hobbies and social activities appeared to be important for perceived psychological well-being. Therefore, enhancing self-efficacy in H&N cancer patients and their partners, by means of self-management programs for chronic diseases, seems a worthwhile research area.

Limitations

When interpreting the results, several limitations should be mentioned. First, the current study was cross-sectional, thus no conclusions can be drawn about causality. Moreover, the small sample size hampered the use of multivariate statistics. The specific characteristics of the participants may also limit the generalizability of the findings. We included only male patients and their female partners within a fixed period of time from diagnosis and treatment. Despite these limitations, our results add to an underexposed subject of the impact of H&N cancer on caregiver relationships. The study enabled us to understand patients and their partner's perceptions regarding personal goals in life in an in-depth way. Furthermore, this study was strongly driven by the self-regulation theory. Future longitudinal research, using a larger sample, is needed to confirm our findings and further examine the role of self-regulation variables in the psychological adaptation of cancer patients. Dyadic analyses could be of added value, including attention to the seemingly important role of gender in individual distress levels (Hagedoorn et al., 2008).

Implications for clinical practice & nursing

While the necessity of psychological support has been recognized, it is still rare in H&N cancer units, mainly due to lack of resources required to develop psychological services (Humphris, 2008). Before starting any interventions, a structured screening to assess the levels of distress and needs for support is of key importance. Specifically for H&N cancer patients an efficient aid in screening and referral of patients with psychosocial problems has been developed (Pruyn et al., 2004). It has been proven that this instrument leads to a reduction in consultation time and increases specialists' initiative to discuss psychosocial problems and could be complemented with screening questions related to self-regulation abilities.

Possible psychological support could be seen in self-management programs emphasizing the patients' central role in managing their illness (Lorig et al., 2001). Examples of such programs enhancing the patient's self-efficacy include psycho-educational interventions, cognitive-behavioral interventions or group interventions (Hirai et al., 2002). One specific intervention developed for chronically ill patients is the generic Chronic Disease Self-management Program (Lorig et al., 2005). As our findings indicate that self-regulation abilities such as goal re-engagement and self-efficacy play an important role in psychological well-being in H&N cancer patients and their partners, it seems obvious to target possible future interventions on increasing these capabilities. Before treatment, additional information in the form of a leaflet or DVD (Schofield et al., 2008) could be given, specifically related to psychological consequences of H&N cancer that enhances self-efficacy. An H&N cancer nurse or a psychologist could give information and train patients and partners to engage in attainable life goals and to increase self-efficacy capabilities. A pilot study testing the feasibility of providing a psycho-educational intervention for H&N cancer patients has shown to have beneficial effects (Allison et al., 2004). Also support groups for patients and partners seem to improve well-being in various areas such as emotions, pain and enhancing self-efficacy (Vakharia et al., 2007). Future research is needed to confirm the current findings which could serve as the basis for possible psychosocial interventions aiming at increasing psychological well-being of H&N cancer patients and their partners.

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Conflict of interest statement

The authors have no conflict of interest.

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